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ABSTRACT

When elderly persons can no longer care for themselves, they usually have only two primary options: care at home by unpaid relatives or high cost care in a nursing home; it is clear, then that a new system is needed that will offer older people more options. This report presents the major policy questions America faces in the search for a better way to guarantee dignity for the frail elderly. Long-term care is defined and reasons why America's present long-term care system needs to change are discussed. A section on moving toward a better long-term care system considers who has responsibility, what the best structure might be, and the influence of national values and economic considerations. The roles of the private and public sectors in providing long-term care are examined and a public/private mix is considered. Other sections look at protecting families and the poor, and also at payment strategies to assure more options for the elderly, including prospective payment, client-centered reimbursement, case management, and combining the financing and management of care. The report concludes by identifying the challenge that lies ahead in this area. A discussion of current actions being taken by state government and a list of speakers at the 1988 American Society on Aging conference "Conflicts in Care: Critical Debates in an Aging Society" are appended. (NB)

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LONG TERM CARE

Who's Responsible?

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Critical Debates in an Aging Society Report No. 2

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American Society on Aging

Critical Debates in an Aging Society: No. 2

LONG TERM CARE
Who's Responsible?

In January, 1988, ASA convened "Conflicts in Care: Critical Debates in an Aging Society." That conference, bringing together nationally respected speakers who represented the widest spectrum of views, examined the questions this publication addresses (see Appendix B for list of conference speakers). We thank them for their contributions and wisdom and their willingness to grapple with these difficult issues. We also wish to thank Martha Holstein, Lora Connolly, Judy McLean, Mary Girouard and Marcia Freedman for their invaluable assistance in preparing this report.

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The American Society on Aging is a 8,000 person membership association of those who work with and for elders. ASA conducts training and education programs for professionals in aging, publishes a quarterly journal, *Generations*, and a bimonthly newspaper, *The Aging Connection*, and these "Critical Debates in an Aging Society." Through its publications and programs, ASA disseminates information and provides a forum for the discussion of policy and other critical issues of our time.

Critical Debates in an Aging Society Series
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INTRODUCTION

Americans are living longer, and a growing percentage are living for more years with chronic, disabling illnesses. When these elders can no longer care for themselves, they usually have only two primary options. The first is care at home by unpaid relatives, the second is high cost care in a nursing home. In some communities, however, community-based care options are emerging.

Not only is the supply of unpaid relatives going down while the number of elders needing care is rising, but such family members often feel tremendous stress and conflict. As women—the principal caregivers—enter the paid work force in ever increasing numbers the supply of unpaid caregivers will continue decreasing.

The other major and generally available option is nursing home care. However, most elders dread the nursing home. And nursing home care is very expensive; to pay for it many older people are forced into poverty which, in turn, squeezes state and government budgets.

Clearly, America needs a new system, one that offers older people more options. Yet despite widespread discontent with our present arrangements, there is no national consensus about what a new system would look like, or how to go about creating it.

"Long-Term Care: Who's Responsible?" presents the major policy questions America faces in our search for a better way to guarantee dignity for those among us who become frail in old age.

LONG-TERM CARE: MORE THAN THE NURSING HOME

Long-Term Care Defined

What is long-term care? Most simply, it is care given for a chronic illness or disabling condition over a long period of time. The phrase "long-term care" generally is used to mean care designed to manage a disease rather than to cure or provide rehabilitation.

People who need long-term care are unable to perform for themselves the tasks of daily living. They need help getting out of bed, walking, bathing, dressing, using the toilet, eating or taking medications. Or they may have some limitation that keeps them from being able to do things like shop or prepare even a simple meal.

Many Americans have only one image of long-term care: that of the nursing home. Nursing home care, including care in similar institutions, is a type of long-term care. But far more long-term care happens at home than in nursing homes. The phrase "long-term care" is useful in that it serves as a reminder that when people have disabling illnesses, there are other solutions besides the nursing home.

Long-Term Care Touches Us All

Long-term care for the elderly is perhaps the public policy issue that most deeply and personally touches the lives of Americans. The need for long-term care and the difficult and often painful decisions that accompany its provision cut across all segments of our society and all age groups: grandchildren deeply concerned about their grandparents' well-being; adult children torn between their children, their jobs and their frail parents; older people anxious about the day they can no longer care for their husbands or wives and the high cost of anyone else doing it; and the frail elderly themselves, ardent in their desire to remain independent and not become a burden to their families, yet knowing they may need costly care.

A 1987 national poll conducted by the Villers Foundation and the American Association of Retired Persons reveals that the need for long-term care is a growing national family crisis.

▼ Over 60% of those polled have had direct experience with the need for long-term care.

▼ Almost half said they or a family member have need of long-term care. Even among those without personal experience, more than half anticipate that a family member would need long-term care within the next five years.

Long-term care is primarily the concern of older people and their families, but it touches all age groups.

WHY AMERICA'S LONG-TERM CARE SYSTEM NEEDS TO CHANGE

America's system of long-term care is in the midst of a crisis and there is a growing national perception that the need for change is urgent. First, our present system is on a collision course: A growing number of Americans who will need long-term care will have an increasingly difficult time obtaining the kind of care they need and want.

Second, the present system is costly. The current methods of payment force many older people into poverty and squeeze the budgets of state governments.

Finally, older people and their families don't like our present long-term care system.

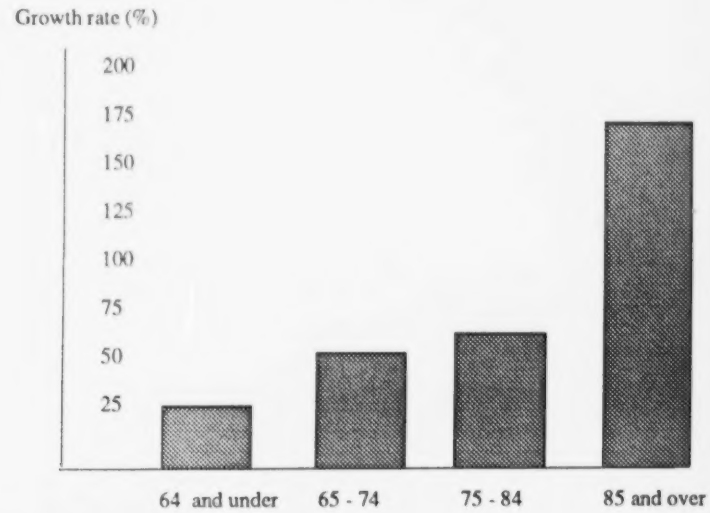
A Growing Number of Americans Need Long-Term Care

Dramatic shifts in America's population foretell large increases in the need for long-term care. The number of elderly Americans has grown rapidly during the past decade. Even more important, people over age 85 are the fastest growing segment of the older American population (see Table 1). Four out of ten Americans now age 65 will live to age 85, and between 1990 and 2010, the number of people over 85 will grow 3 to 4 times as fast as the general population. These "oldest old" people will need far more long-term care services than the younger old.

Today, approximately 21% of the 28 million Americans over 65 need long-term care services—a total of 6.6 million. By the year 2024, this number will probably increase almost three-fold, to 19 million.

Most Americans who need long-term care are not in nursing homes; today 71% live in the community with assistance and 29% are in nursing homes. And though this report focuses on older people, it should be noted that about 40% of the total population who need assistance (included in this statistic are the developmentally disabled) are under the age of 65. Moreover, we have yet to understand fully the impact of AIDS on

Table 1.
Change in Age Distribution in the United States Population, 1960-1980



Source: S.L. Hughes, *Long-Term Care Options in an Expanding Market* (Aspen, 1986), p. 72.

the need for long-term care services (see Fall 1989 *Generations* on "AIDS & an Aging Society").

Profile: Elders in Nursing Homes

Between 5%–9% of the total elderly population lives in nursing homes at any given time. For those age 85 and over, the percentage more than doubles. Twenty-three percent of all nursing home residents are over 85.

The nursing home resident's median age is 81; 71% are female, and 81% are widowed, divorced or were never married. Some are short-term and some long-term users. Short-term users, who are discharged within a year, are generally younger, married elders who have an acute illness or condition, predominantly hip fractures (67%) and/or cancer (40%). Long-term users are generally the "older old," and are predominantly widowed or single women. They most often suffer from incontinence or organic brain syndrome, a mentally disabling condition that used to be mislabeled as "senility."

Profile: Elders Receiving Long-Term Care in the Community

However, most elders who need long-term care live in the community. This population is more diverse than that in nursing

Table 2.
Rate per 1,000 Adults Who Need Assistance at Home by Type of Need, Age, and Sex, United States, 1979

		Age and Sex							
	All Adults	55-64 Years		65-74 Years		75-84 Years		85 Years +	
		M	F	M	F	M	F	M	F
Type of Need									
Needs help in one or more basic physical activities	22.5	28.0	29.3	49.4	29.3	101.7	121.4	301.7	372.0
Walking	16.1	20.5	17.6	37.7	17.6	73.5	89.7	204.8	289.7
Going outside	13.7	12.2	15.9	28.0	15.9	52.6	86.2	225.3	292.7
Bathing	9.1	10.5	11.6	22.8	11.6	45.6	53.7	149.0	185.5
Dressing	7.1	8.7	9.0	14.3	9.0	31.3	34.1	111.7	118.1
Using the toilet	5.5	6.0	6.0	12.0	6.0	22.0	32.0	72.6	122.0
Getting in or out of bed	4.9	6.1	5.9	8.0	5.9	20.1	29.2	63.3	78.4
Eating	2.0	4.0	1.6	5.2	1.6	7.3	9.1	33.5	39.7
Adults who usually stay in bed	5.5	9.0	7.0	11.9	10.9	29.4	27.6	61.5	45.6
Has device or other trouble controlling bowels or bladder	10.1	8.7	16.3	14.6	28.8	49.1	49.0	117.3	108.1
Needs help of another person in one or more of the above activities	31.7	34.3	45.3	55.3	81.1	127.6	180.8	353.8	479.2
		Both Sexes							
Needs help in one or more home management activities	26.5		31.9		57.3		141.8		399.0
Shopping only	4.0		4.1		11.1		25.6		71.2
Chores only	3.8		7.1		9.0		12.1		26.6
Meals only	0.5		0.9		1.3		2.3		5.8
Shopping and chores	3.4		4.1		7.6		23.6		43.4
Meals, shopping, chores	4.1		6.6		10.4		18.3		60.9
No help reported needed	973.5		968.1		942.7		858.2		601.0

Source: National Center for Health Statistics, "Americans Needing Help to Function at Home," *Advance Data*, No. 92, September, 1983.

homes. As Table 2 (see page 6) indicates, they generally require assistance with mobility or personal care (bathing, dressing, using the toilet or eating). This need for assistance increases with age. Because women live to older ages, more women need assistance than men. Family members provide 88% of care outside of institutions informally, and it is their availability, rather than the type or extent of disability, that often means the difference between home-based or institutional care.

The Present System Is Too Costly

It is estimated that families (wives, husbands, daughters, daughters-in-law) and friends provide 88% of all long-term care on an informal, unpaid basis in the community. This suggests that one of the important tasks of public and social policy is to support the family in what is often a difficult task. A small percentage of elderly people receive care services at home from professionals. These can be from private agencies, financed by the elder or his or her family. There are also some programs financed by federal, state and local governments that provide care at home.

Long-term care, no matter the source of the dollars, is very costly. In 1984, American elders paid $15.8 billion for nursing home care, over $3.5 billion for home care, and $1.7 billion for long-term care in hospitals. Individual elders paid for almost half of nursing home costs; Medicaid covered over 43% of the total costs. In 1985, one third of total Medicaid spending, approximately $14.7 billion, was for nursing home care. And these public expenditures do not include the contribution from Medicaid nursing home residents' Social Security pensions.

High Cost to Elders

Care in an institutional setting easily exceeds an annual cost of $22,000, forcing many nursing home patients (and their spouses, if they are married) to use their entire life savings to pay for care. Medicare and most health insurance policies do not cover anything but minimal long term nursing home services. The only public assistance available comes from Medicaid, a

ANNA WILLIAMS

ARTHUR P. STANLEY

Most elders who need long-term care are not in nursing homes; 71% live in their communities.

program designed to serve the poor. To get any help from Medicaid, the nursing home patient must become totally impoverished. The process of reaching poverty to qualify for Medicaid nursing home benefits is called "spending down." A recent House Aging Committee report notes that nearly 70% of the single elderly spend down all their assets after only 13 weeks in a nursing home. Typically, it takes six months to reduce a couple to poverty. Table 3 illustrates the rate of spend down for couples and single elders at ages 75 and 66. Older people, it can be seen, reach poverty faster.

High Cost to State Governments

In 21 states, long-term care currently consumes more than 40% of all Medicaid expenditures. Since many recipients who spend down are originally middle class elders, the basic intent of the Medicaid program, to ensure access to medical care for the poor, becomes distorted. Medicaid and other health care programs are the most rapidly rising component of state budgets. States have aggressively attempted to reduce the escalation of Medicaid expenditures in recent years, since program costs continue to rise faster than states' revenues. To offset these growing costs, in addition to eroding Medicaid's benefits or limiting program eligibility, states have been forced to make painful cuts in other critically needed programs.

Projections of future need for nursing home care strongly suggest that both the need and cost will continue to grow at a rate that outpaces increases in states' revenues. Medicaid nursing home reimbursements alone are projected to be $55.1 billion by 1990. A recent Health Care Financing Ad-

Table 3. Risk of Spend Down to Medicaid Eligibility among Different Elderly Subgroups

	Percent of Elderly Meeting Spend-Down Criteria over Time (Weeks)					
	0	*13*	*26*	*39*	*52*	*104*
75 years and older*						
Live alone and institutionalized	7	46	59	66	72	85
Married couple, one of whom is institutionalized	2	25	41	43	57	82
Married couple, one of whom requires extensive home care due to Alzheimer's†	2	11	25	30	41	52
66 years and older						
Live alone and institutionalized	8	63	74	80	83	91
Married couple, one of whom is institutionalized	4	37	47	53	57	80
Married couple, one of whom requires extensive home care due to Alzheimer's‡	4	16	33	39	47	55

*Based on data from the Massachusetts' Health Care Panel Study, based on an estimated $75 per diem cost of care.

† Based on estimated 6.28 hours of homemaker or home health aide service/day as per findings of Hu, Huang, and Cartwright and calculated at the rate of $5.69 per hour.

‡ Based on data from the Framingham longitudinal study.

Source: Lawrence G. Branch, Daniel J. Friedman, and Elinor Socholitzky, testimony before the House Select Committee on Aging, July 30, 1985.

ministration study suggests that if Americans continue to enter nursing homes at the current rate, the number of nursing home residents will increase 54% by the year 2000. Clearly, elders and their families will find it more difficult to pay for escalating nursing home costs, thus leading to increased dependency on state and federal programs. That will leave state and federal governments with the choice of drastically cutting care or substantially raising their tax bases. The future costs alone dictate the need for change in our system of long-term care.

Older Americans Don't Like the Present System

The most important reason for changing our present system is that neither elders nor their families like it. The system has a strong bias toward the option elders dread most: the nursing home. Overwhelmingly, older Americans want both to remain in their own homes and not burden others.

The present system has problems of equity and access, too. A formerly middle-class elder who has "spent down" his or her resources on nursing home care may find that the nursing home will no longer keep him or her as a patient once Medicaid financing begins. People who must begin their nursing home stays on Medicaid find that many nursing homes do not accept them. Spend down requirements can mean that a husband or wife of a nursing home patient must also become impoverished. This has led to the problem of the formerly middle class wife living on as a widow in poverty. When her husband became disabled, the couple's entire life savings had to be used to pay for care. Since women live longer than men on average, more wives than husbands meet this fate. Spousal impoverishment protection in a number of states and in the federal Medicare Catastrophic Protection Act is a partial response to this unacceptable outcome.

The United States places a higher percentage of its elderly in medical model long-term care facilities than any other industrial nation in the world. Most of these elders (70%–80%) are in nursing homes not because of medical reasons, but because they can't perform simple tasks of daily living. In revising America's long-term care policy, we must ask why we institutionalize so many, and what we can do to reverse that trend.

FLORENCE S. ROSEN

The most important reason for changing our present system of long-term care is that neither elders nor their families like it.

TOWARD A BETTER LONG-TERM CARE SYSTEM: ASKING THE RIGHT QUESTIONS

American policy toward the care of those with chronic illnesses has evolved incrementally and disjointedly. Care outside of nursing homes has been made available through a patchwork of add-ons to other pieces of health and social legislation, as evidenced by the funding maze illustrated in Table 4. There is no coherent policy for organizing and financing long-term care. Evaluated by ethical, economic or political standards, the care we purchase at great cost most often does not meet the minimal expectations of the payer, the provider, or the consumer. Demographic trends accelerating the demand for services will only exacerbate the inadequacies of the current programs.

Over the last decade there has been much study and discussion about long-term care at the federal level, yet the service delivery system and financing mechanisms have undergone little substantive change during the past 25 years. What has changed is the national perception of the urgent need to reach rational and permanent solutions to our long-term care problems.

While a consensus is developing that the United States urgently needs a comprehensive long-term care system, there is considerable debate and discussion about how best to do it.

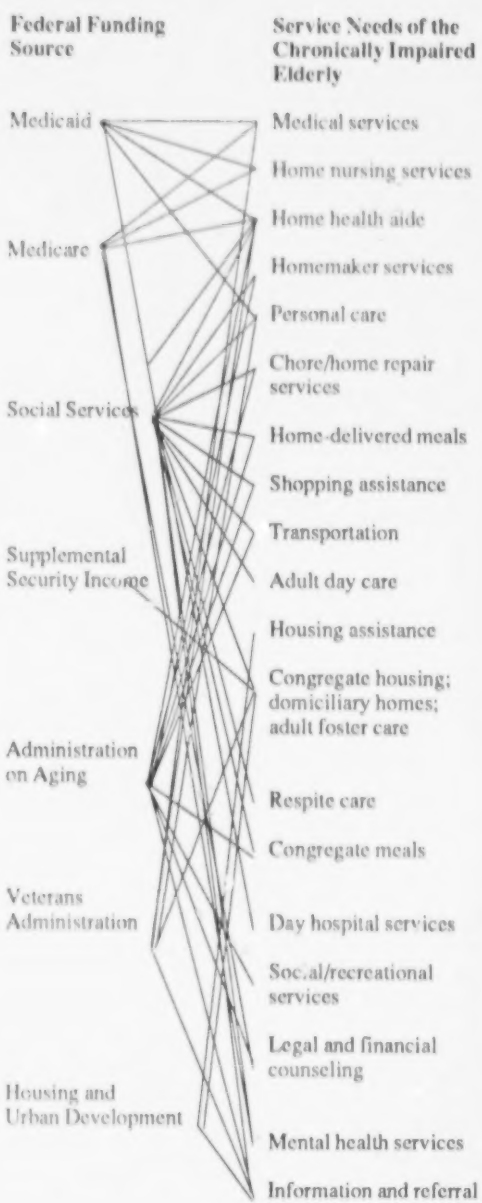


Table 4.
Major Federal Programs Funding Community Services for the Elderly

Source: Meyer Katzper, *Modeling of Long Term Care* (Dept. of Health and Human Services, 1981), p.16.

Who Has Responsibility?

The most basic question asks who has primary responsibility for providing and paying for care. Should it be elders and their families? Or is a social insurance program, with the government playing a primary role and private efforts supplementary, the appropriate model? Or should the program be a public/private mix, depending on income?

Related Issues

Related issues include: Who should provide the services and where? How do we assure that the needs and wishes of elders are honored? Is home care better than institutional care? What types of services should be offered? Who should be eligible, and on the basis of what criteria? How do we assure access to care for those who are poor? How can quality of care be monitored successfully? How will we assure an adequate number of trained and dependable personnel? How do we finance long-term care during a period of fiscal austerity?

What Is the Best Structure?

Equally important, what is the best structure that will enable us to go forward with a system that is sustainable over time, that is relatively simple to administer, that assures adequacy, not just for the frail and vulnerable today but for those in coming generations? We need to create a system that insures maximum dignity, autonomy and independence.

The Trap of Economic Considerations

In recent years, economic considerations, couched in cost-benefit and cost-effectiveness language, have dominated long-term care discussions. Long-term care is often viewed as a commodity; spoken of in terms of "market shares," with patients as "consumers." While economic considerations are important, they do not stand alone when describing the exchange that takes place when a person is sick, disabled and frail. Cost containment is not the primary social goal. Nor are economic values sufficient, in themselves, to provide an ethical basis for policy choices.

We must recognize and address many other considerations, such as autonomy and justice, in our search for a long-term care policy. We must ask questions not only about the elder but also about families: How do we balance our aid to families so that programs neither usurp the family's natural caregiving role, nor place demands on family members that are destructive to their physical and emotional health?

Reflecting Our National Values

Long-term care is both a social and a public policy issue. It affects every institution in our society: the family, the workplace, the community and the government. All of these entities must be involved in the development of whatever system evolves. The challenge to policy makers is to fashion a system reflecting the diverse values and aspirations of the American people. At the root of our social values must be the empowerment of those who are frail. As a society we must develop a long-term care system that gives people opportunities and alternatives so that they and their families can flourish.

SAM SEICOL

While economic considerations are important, they do not fully describe the exchange that takes place when a person is sick, disabled and frail.

THE LEADING PLAYER: PRIVATE SECTOR OR PUBLIC SECTOR?

Liberal, conservative or moderate, almost all will agree that something must be done about this nation's present long-term care system. Many in federal and state government and in the nursing home industry argue that the private sector should be the leading player in creating change. They believe that the system is basically sound and only the method of financing needs restructuring. The public sector should spend less and the private sector, principally individuals, ought to shoulder more of the cost. Underlying this approach is the belief that long-term care is primarily a private family matter, and that the government's role is to make it easier for individuals and families to provide for their future needs. If elders and their families want a broader range of services than nursing home care, they will create a demand for them and the private sector will fill it. However, individuals would bear financial responsibility.

Others, however, argue that manipulating essentially private financing mechanisms will not solve the basic problem. This group argues that as a society, we all share responsibility for the care of the old. They believe that only the public sector, unfettered by the requirement that every service turn a profit, can develop what America needs: a comprehensive long-term care system that is responsive to the needs of our older citizens with chronic illnesses.

Whether the private or public sector becomes the leading player, both sides admit that long-term care will continue to consume greater amounts of the federal budget. Even if we choose to do nothing more than at present we will still be forced to spend more.

BONNIE LONG

A continuum of care means providing services that allow older people the greatest possible autonomy.

The Continuum of Care

The underlying question is how best to encourage a system that gives older people maximum independence, allowing them to remain, as long as possible, where they want to be: in their own homes.

This means providing a variety of services, known as the *continuum of care*. At one end of the continuum are elders who need very little assistance. Perhaps a family member who provides care could use a weekly four-hour break. Or perhaps the older person lives alone, but needs help getting food into the home and undertaking heavy household chores. At the other end of the continuum is an older person who has lost almost all ability to care for him/herself and needs almost constant care. At every point along the continuum, the goal is to provide services that allow the older person the greatest possible autonomy. Because this means offering social, as well as medical, services, this is known as the *social model* of care.

These services include respite for family members who care for an elder, including day care centers where the elder can spend a substantial part of each day, and aides who will substitute for the family member in the home.

They also include services provided directly to older people at home: medical and nursing care; aides who can assist with medications, with personal care such as bathing and using the toilet, with house cleaning and chores; meals prepared in the home or delivered; and transportation.

In addition, a range of housing options will allow more choices than private home vs. nursing home. Congregate housing allows each elder to have a separate living area, while common areas are set aside for meals, recreation, and sometimes adult day care or temporary skilled nursing care. Board and care homes and adult foster care would be other options.

THE PRIVATE SECTOR AS LEADING PLAYER

Underlying Values

Those who endorse a primarily private sector response are guided by values rooted in the American tradition of individualism. They believe that:

▼ Individuals are principally responsible for their own care and planning for that care.

▼ Families bear important financial responsibilities for long-term care. As children are cared for and nurtured by their parents, they in turn should assist their parents when they are unable to manage on their own.

▼ Employers already play a major role in providing life, health and retirement benefits, and should do so. The employer-employee relationship is an important source of low-cost protection and employers should be involved in financing long-term care for retirees and their spouses and for elderly dependents of current employees.

▼ The role of government, both state and federal, should be limited to providing care for those unable to afford care for themselves; providing incentives that encourage individuals, families and employers to meet long-term care needs; and regulating financing mechanisms and service providers to prevent abuse, exploitation or inferior quality.

Current Economic Trends Favoring a Private Sector Approach

Two current economic trends also spark interest in the private sector approach. Large federal deficits make Congress reluctant to consider major new public expenditures, which would be necessary with a publicly-funded long-term care system. The other trend is the significant improvement in the financial position of America's elderly over the past two decades. Many older Amer-

MARIANNE GONTARZ

Families now bear more than half the financial responsibility for long-term care; a private-sector approach would spread those expenses over a larger number of people.

icans may have the means to finance long-term care privately.

Private Long-Term Care Insurance: The Case For

The centerpiece of a strategy to shift responsibility for long-term care to individuals is private long-term care insurance. Widely available insurance would encourage individuals to plan and pay for long-term care in advance. For those who can afford them, private insurance plans would provide protection from the impoverishment that currently all too often accompanies the need for long-term skilled nursing care.

Easy to Set Up

Long-term care insurance builds on the well-known willingness of elders to buy Medigap insurance (which covers the difference between Medicare reimbursement and actual costs). It does not require a new organizational structure, and so can be expanded relatively quickly into a major financing source.

Long-term care insurance would spread the risk of high costs across a broader population than a system solely financed, out-of-pocket, by individuals. It is non-compulsory, and provides great flexibility in meeting individual needs.

A Personalized System

We can expect that increased competition among long-term care insurance carriers will lead to more comprehensive programs, coverage of more services, and an integration of the delivery and financing systems. Consumers of long-term care services want financial protection, the ability to stay at home, services that will mesh with their informal care system, and access to the services they want when they need them. In essence, consumers are looking for a very personalized system. Government historically has shown itself to lack flexibility in providing services. The private sector, driven by consumer preferences, is more capable of providing this personalized service mix.

Private Long-Term Care Insurance: The Case Against

Adverse Selection

Only people who need long-term care insurance will purchase it, driving up utilization and the price of the policies. Insurers try to protect themselves against this by screening for health conditions, prohibiting coverage for pre-existing conditions, excluding coverage for mental conditions (it is not clear that available policies cover Alzheimer's disease), providing reimbursement only if there is a prior hospitalization, and marketing principally to the affluent.

Bias Toward Nursing Homes

One of the consequences of insurance is that it lowers the effective price of services, leading to greater consumption. To protect themselves from this "hazard," insurers may create high deductibles and restrict the coverage, especially for home care. Unfortunately, high deductibles limit protection and the exclusion of home care may exacerbate the already strong bias toward nursing homes that hobbles the current financing system.

Inadequate Benefits/Inflationary Potential

Another critical flaw with the private insurance alternative is that policy reimbursement levels rarely increase with inflation. Adequate benefits today will be inadequate in the future. Long-term care insurance may even fuel the inflation that decreases its value. Third party payment for acute care has been partially responsible for rapidly rising hospital and physician costs. Long-

term care insurance may have a similar inflationary effect.

Uncertain Market

Most Americans substantially underestimate their chance of long term disability. Many older people mistakenly believe that Medicare and/or their Medigap insurance policies cover long-term care. The Medicare Catastrophic Coverage Act of 1988 will probably only add to consumer misunderstanding. Further, the insurance industry believes that a large number of elders will not buy private long-term care policies because of the availability of, and their willingness to use, Medicaid as a "safety net" to pay for nursing home care. This uncertainty may drive up the marketing costs.

Cost

Premiums are high, thus limiting the market. A Brookings Institution study estimated that even with generous assumptions about who would be able to participate, only 26%–45% of elders could afford private long-term care insurance policies. They estimated that this would account for only 7%–9% of total U.S. nursing home expenditures, and might reduce Medicaid expenditures in nursing homes by at most 2% to 5%.

Exclusions

Policies that are currently available do not cover many of the conditions that lead to elders entering nursing homes. A recent study conducted by the United Seniors Health Cooperative and the University of North Carolina indicated that 25%–80% of people in nursing homes would not be covered, even if they had purchased private long-term care insurance, due to restrictions and limitations. Although policies will be improved, based on experience and consumer demand, these improvements may drive up premium costs.

CHRISTINE BECKER

Only 26%–45% of elders could afford private long-term care insurance; middle- and low-income elders would be left behind.

OTHER PRIVATE SECTOR OPTIONS

Employer Initiatives

Within the past few years, employers have become aware of the absence of and need for long-term health coverage for employees and retirees. Employers are motivated by concern over lost productivity and an awareness that more workers are now women, who traditionally have cared for husbands or parents. Some employers have responded with new benefit options. Although most are experimenting with private long-term care insurance, a few have provided more innovative benefits. IBM, for example, has developed an elder care referral service that links care providers with those needing care. Employers are also adopting scheduling policies, such as flex-time, that make it easier for workers to meet their family care and work responsibilities.

Employer-Provided Long-Term Care Insurance

Employers are experimenting with three types of benefits. The first is making group plans available with premiums paid entirely by the employee or retiree. Procter & Gamble uses this approach. The corporation based its plan on previous success with a human organ transplant insurance benefit, with employees paying the entire premium. In three years, 88% of their employees had enrolled. Procter & Gamble decided to offer long-term care insurance coverage with a comparable payment arrangement. The first year enrollment figures are surprisingly high, with more than 14% of all eligible employees participating. Twenty percent are ages 40 to 59, countering the argument that long-term care insurance does not appeal to the middle-aged.

With the second type of benefit, employers offer a flexible benefits plan, with one option being employer contributions to long-term care insurance. This type of financing often is provided on a pre-tax salary reduction basis. The problem with retirees is that, according to law, employer contributions are considered as income to the retiree and are therefore taxable. Nor can current workers buy into the plan for their parents. However, it is potentially a significant area of benefit expansion for current employers.

The third type of potentially valuable benefit involves employers contributing coverage for long-term care as part of a trade-off for employees and retirees sharing more of the cost of other company-provided health or pension benefits.

The Case For

Employer-sponsored group plans build on the tradition of employers providing health insurance. As the Procter & Gamble study shows, they may help clear up consumer confusion and lead to more people enrolling, thus spreading risk more widely.

The Case Against

Employment is not the appropriate way to distribute what is increasingly becoming a social service, not a negotiated benefit. The majority of workers probably won't have access to an employer-sponsored long-term care insurance benefit. Only a small fraction of workplaces—primarily among the largest corporations—are considering innovative long-term care benefits. Meanwhile, the

growth in employment occurs in areas of the economy that pay the minimum wage and offer no benefits. Small businesses, where the majority of Americans work, even reject providing health benefits for employees. Over 40 million Americans currently have no health coverage and the number rises every year. Patterning a long-term care strategy on a failing health benefit system will leave America unable to provide access and equity to even the majority of elders.

Continuing Care Retirement Communities

Continuing care retirement communities (CCRCs) are financially self-sufficient settings for elders that combine housing with medical, nursing, and social services in specialized facilities on the premises. The underlying concept is pooling risk to provide a lifetime continuum of care. CCRCs typically require a large up-front payment of $60,000-$100,000, and monthly fees of $1,000 or more.

The Case for CCRCs

These communities combine an organized system of care with financial incentives for cost effectiveness in an insurance-like setting of pooled risk. Quality of life may be enhanced; by having a relatively large number of elders in one place, CCRCs may be able to provide in-home services less expensively and forestall or prevent the need for nursing home care. However, when nursing home care becomes necessary, it is available right in the same housing complex, thus minimizing the stress associated with relocation.

The Case Against CCRCs

CCRCs are expensive, thus narrowing their importance as a solution for any large percentage of America's elders. They usually restrict entry to only healthy older people, thus excluding those most in need of long-term care. In some cases, CCRCs have been financially unsound and have gone bankrupt. Older people who have spent their life savings to join these CCRCs have been left

MARIANNE GONTARZ

Continuing Care Retirement Communities combine housing with long-term care services in specialized facilities right on the premises. But some elders have lost their life savings when they paid hefty fees to join, only to have the retirement community go bankrupt.

stranded. As real estate speculators become more involved, this risk increases. Many CCRCs have started to charge additional fees for intensive services; therefore, they do not fully protect against nursing home expenses. Finally, most older people do not want to leave their own homes and move into this type of highly organized setting.

Home Equity Conversions

About 70% of all elder households own their own homes. Even among low income households, about 65% own their own home. Home equity conversion changes assets invested in a home into a stream of income, which is then available to meet long-term care needs. A bank gives the homeowner a loan, which is paid to the homeowner in monthly installments. At some time in the future, usually after his or her death, the homeowner (or the estate) repays the loan with interest, using the proceeds from the sale of the home.

The Case for Home Equity Conversion

This method is a relatively painless way to increase elders' income and provide them with funds for long-term care. Studies have estimated that the amount of money that could be generated by converting home equity to cash is substantial. This is the one private sector option that could benefit many lower income elderly people. It would also assist a group most at risk of nursing home placement—those who are living alone and are very old.

The Case Against Home Equity Conversion

Elders are generally unwilling to let go of their home asset. In addition, since the home is the only asset an elder does not have to "spend down" to qualify for Medicaid, a policy that consumes an elder's principal asset in order to forestall the need for Medicaid would seem perverse. There is a trade-off between the comfort and security of maintaining ownership of one's assets and the potentially short-term savings to Medicaid.

MARIANNE GONTARZ

About 70% of elder households own their own homes. Can their home equity be a source of funds for long-term care?

Financial lenders also perceive significant problems. If elders outlive their actuarial expectancy, financial institutions would have to foreclose or postpone claiming the asset. Neither option is very attractive. The evolving consensus is that there is a need for public mortgage insurance.

With home equity conversion, the financial burden of long-term care remains with the individual. There is no attempt to spread the risk across a larger population. Moreover, although it may generate enough income for the individual to purchase private insurance, the income generated would in most cases be insufficient to cover a long period of care, either at home or in a nursing home. In cases where there is a surviving spouse, the potential for harm is significant, for there would be neither much remaining income nor the home as an asset.

Individual Medical Accounts

Individual medical accounts (IMAs) would be designed to encourage people to save for their own long-term care needs by deferring the taxes on money placed in these accounts. After age 65, these funds would become available to purchase medical and social long-term care services.

The Case for IMAs

Private savings generated from IMAs could reduce the financial risk to older people. They would also have the flexibility to purchase the service package most appropriate to their needs. Because they were purchasing their own care, older people would have incentives not to use unnecessary services and to seek cost effective alternatives. IMAs could also stimulate the long-term care industry to develop a wider range of better quality long-term care services. Since funds could be used for any service, the institutional bias of some other options could be avoided.

The Case Against IMAs

It is not clear that people are willing, or able, to save for a single purpose. They would have to start at early ages to accumulate enough assets so the IMA would be useful. Few people anticipate disability in later life. Only a minority of taxpayers currently claim IRA deductions. Compared to other nations, America has a rather low savings rate. Tax incentives to encourage Americans to save, such as IRAs, have had insignificant results. Taxpayers have merely moved money into tax deductible accounts at a substantial loss to the federal treasury. Tax incentives are an inefficient way to achieve social goals, since they subsidize a group of people who were already doing what the tax incentive sought to have them do.

Public Social Insurance: The Case For

Public social insurance is the only approach that can assure universal and adequate coverage for all Americans. Private insurance, as we have seen, would do little to help disabled, poor, and even most middle-class elderly Americans; they could neither afford nor qualify for the insurance.

Once middle-class elders used up virtually all their personal resources, they could only turn to Medicaid. But few elders feel comfortable with this; middle-class elderly especially find it demeaning to become dependent on a "welfare" program. A dual system is also unfair to the poor. They would continue to receive substantially less and poorer quality care. Middle-class dependence on Medicaid also means that fewer dollars are available for medical care for poor, younger people. Ultimately, depending on Medicaid to finance long-term care distorts the very intent of means-tested programs. Medicaid was designed to serve poor people in need of primarily short-term medical care, not largely middle-class elders who require high cost long-term care services.

Spreading Risk Equitably

A public insurance system would also spread risk more equitably. Private insurance controls risk by screening out high risk people and by limiting policy coverage. With a public insurance system, a large number of beneficiaries who will not use the benefit balance the costs of those who need expensive services. The need for long-term care is not a rare event affecting only a few people. Approximately 50% of all Americans reaching the age of 65 will spend some time in a nursing home before they die. However, half of all nursing home admissions will be for less than three months. Only a small proportion, about 10% of elders, stay over a year. But it is this group

A public insurance system is more likely to provide the kind of services that allow older people to remain at home, and not in nursing homes.

that uses 90% of nursing home resources. The average total nursing home cost for people who stay for one year or longer is estimated at $100,000.

Other Advantages

A public insurance system is the only way to build an effective care delivery system, manage the available resources, implement a strong preventive care component and integrate the long-term care system with America's acute health care system. It is more likely to provide a flexible range of services, including social services, that allow people to remain living outside of nursing homes. Private insurance will, most likely, remain tied to a defined benefit, and nursing home stays are much easier to define.

A public insurance system is also the only effective way to control costs. Canada, with such a system, has controlled long-term care costs because Canada integrates all parts of the health care system. Only public, progressive financing will be fair to present and future generations. It is also the best way to deliver benefits to today's elders, who do not have the time left to pay for premiums or to build up a risk pool.

Public Social Insurance: The Case Against

A public system is an inappropriate intrusion of government into a private, individual responsibility. It promotes overdependence on government. A universal long-term care insurance system would be another costly burden, like Medicare, eating away at the federal budget.

Many believe that long-term care, because it is predominantly non-medical in its components, is not a public but a private responsibility. This point of view reflects a wish to preserve important distinctions between that which is private and that which is public. Since there are a number of options available to help the individual and the family to cover the costs of this often costly burden, government should not be turned to except as a last resort. This is now the role that Medicaid plays after a person or couple has spent down and thereby meets income and asset requirements.

For a number of people, there is the deep concern that we still cannot predict the total social costs of public funding for long-term care. There have been a number of estimates of what an inclusive program would cost (i.e., a program for disabled people of all ages) but there is an unwillingness to be overly sanguine that costs will not inflate as rapidly as they have for Medicare. This concern is paired with the seeming reluctance of many to asssume the tax burdens to pay for a program that many indicate they support. Since concerns about financing are particularly potent when budget deficits have become the dominant theme in Congress, the cost burden is one to be studied closely.

Although addressed in a subsequent portion of this report, it should be noted that states are considering a variety of long-term care initiatives. These initiatives are using different financing strategies and are covering different population groups. Experiences in the states should provide the federal government with good, practical information.

A Model from Canada

American policy makers, anxious to avoid escalating costs like those that threaten Medicare's solvency, have only tentatively supported a universal, publicly funded long-term care benefit. However, Canada's expansion of its universal health insurance program to include long-term care services can offer some valuable insights for a similar effort in the United States. Canada closely resembles the United States in its age distribution, large geographic area and

the federal/province structure of government, similar to our federal/state structure. As in the United States, a multiplicity of for-profit, voluntary non-profit and public organizations provide long-term care.

Yet we must be cautious in extrapolating from the Canadian experience. Canada has one tenth of the population of the United States. Its federal system has only ten provinces and two territories, so that health care financing and planning is simpler. Other differences include a parliamentary system of government in Canada, with stable civil servants at high levels, and public acceptance of a larger role for government. The Canadian population is more homogeneous than that of the United States. Nonetheless, in spite of these differences, Canada remains the best possible foreign model for the United States.

Canada's System

Prior to the 1970s, Canadian long-term care was a means-tested system, similar to Medicaid in the United States. The current Canadian system is built on the foundation of that nation's universal health insurance programs. The program is similar to America's Medicare, but it does not have Medicare's formidable premiums, deductibles, coinsurance costs and age eligibility.

Canada's system resembles the block grant approach often recommended for the United States. It is funded at the federal level, but each province has primary responsibility for organizing and delivering long-term care. Much of the control is then delegated to even smaller regional units. This allows provinces to tailor the services they offer to local needs.

Although the system varies from province to province, there are some common characteristics. Benefits in most provinces include health care, personal care and social services for functionally impaired people. Services are offered in residential settings, such as nursing homes, and also in the community. Eligibility is based on functional impairment without regard to income. Copayments are designed to leave even the poorest elders with a small disposable income. For-profit facilities are paid on a per diem basis, negotiated annually for the whole province. Non-profit facilities are paid on the basis of prospectively negotiated global budgets.

Lower Nursing Home Costs

In 1982, Canada's public expenditure per nursing home bed averaged the equivalent of $9,600 U.S. dollars, comparable to a combined federal/state expenditure of about $10,000 in the United States. However, the total cost per bed (when out-of-pocket payments are included) was higher in the United States ($18,200). The total cost in the most expensive province, Manitoba, was the equivalent of $15,400 in U.S. dollars. In the Canadian provinces, the costs not picked up by the public program are largely financed by user fees. Each province establishes a fixed per diem ward rate at an amount tied to the minimum public pension benefit. Additional charges for private rooms and specific amenities are permitted, but strictly controlled.

SHARRON BENTLEY

Canada's public insurance system has led to lower nursing home costs.

Free Home Care

Home care in the Canadian long-term care system is free. Home case managers, located in each health district, determine the amount. In some provinces, voluntary agencies provide nursing services, which the provinces purchase at negotiated rates. In other provinces, public health nurses provide home nursing directly. Homemaking services are usually purchased either from nonprofit agencies (e.g., the Red Cross) or from for-profit agencies at rates negotiated by social service authorities in each county.

Effect on Nursing Home Use

In Canada, as with demonstration projects in the U.S., the availability of highly developed community services does not seem to have reduced the supply of nursing home beds, even with active case management. The argument for community care rests on other grounds. A commitment to community care represents a desire to serve older people whose needs are not being met by nursing homes. It is a response to elders' often-expressed preference to remain at home as long as possible.

No Large Jump in Demand for Services

American policy makers express concerns that expanding the home care benefit will lead to runaway use. Yet for a relatively controllable 10% of the nursing home budget, Canada has been able to offer a politically attractive package of home care services. The Canadian experience shows a consistent pattern of demand leveling off after the program has been in place about three years. Community organizations, the Canadian experience has proved, can be more rapidly developed or easily reduced than nursing homes. When the benefit was established, an adequate number of provider agencies quickly became available. When fiscal pressures forced a reduction in funding, limits could be placed on local agency budgets.

American policy makers also fear that a universal long-term care benefit that includes home care will provide a disincentive for families to continue providing the majority of the needed care. This has not been the case in Canada. Canadian families continue to provide strong long-term care support and there is little evidence that the government providing care leads to more elders using nursing homes. While 7% of Canadian elders are in institutions, compared to 5% average in the United States, American states with colder climates have an institutionalization rate closer to that of Canada.

A public benefit does not create a disincentive for community involvement, either. The Canadian long-term care system is heavily dependent on donations. Corporations donate funds and equipment; communities raise funds to build new facilities; families and individuals give their time to deliver meals or drive people to the doctor. All play a significant role in the Canadian long-term care system.

Affordable and Humane

The Canadian system has faced challenges. There is some concern about treatment delays and physician dissatisfaction. Still, the Canadian experience illustrates that both the addition of a long-term care benefit and community-based care can be affordable. It also shows that a publicly financed system would probably be best run at a state level, to permit maximum flexibility in meeting different regional needs.

Canada, in many ways similar to the United States, has developed a social response to the nation's long-term care needs, not only because Canadian elders have earned the benefit, but because Canadians believe it is the role of society to provide for those in need.

A PUBLIC/PRIVATE MIX

The Case For

A public and private mix would combine the advantages of both approaches. A public program would guarantee universal coverage, leaving a substantial market for private insurers. Several public/private strategies have been developed, all with a two-tiered structure similar to that of Social Security and private pensions. On the first tier, an expanded public insurance program would provide everyone a modest degree of financing for long-term care. On the second tier, the private sector would step in with long-term care insurance and other financing mechanisms. These would provide greater protection for those who wanted and could afford it.

One option would be for the public sector to provide nursing home and home care through the Medicare or Medicaid program after a two- or three-year deductible period. Elders would be encouraged to purchase private insurance to cover most of the deductible period. This approach is under discussion in several states, including New York, Massachusetts, Connecticut, Indiana, Wisconsin and North Carolina, as well as in several long-term care financing bills being developed in Congress. A principal assumption is that shortening the coverage period will make private insurance more affordable. Another is that the public sector covering the risky "tail end" of nursing home stays will reduce the financial risk to insurers. This should encourage them to offer long-term care policies.

Another option is a public insurance program that provides a broader set of benefits without a long deductible, but including cost-sharing. Private insurance would cover the cost of deductibles and coinsurance, just as current Medigap policies do for Medicare. Compared to a two- to three-year deductible, this option carries less risk of impoverishment, especially if combined with improved financial protection for the lower income populations. This approach also retains a substantial role for the private sector, but does not depend wholly on massive expansion of private insurance for its success. However, public expenditures would be substantially higher.

The Case Against

America's present system of long-term care already has two tiers, and this is a source of inequity for lower income elders. A public-private mix will do little to alter that. Private insurers would have an incentive to screen out high-risk individuals, insuring those less likely to need the benefits. Those who need care most will be forced to depend on the government program. Large numbers of disabled and lower income elders will find private insurance unavailable. They will continue to spend down to the poverty level to become eligible for Medicaid. Policy makers concerned with protecting the middle class argue that government intervention should not begin on the first day, but somewhere along the continuum. Those who have resources would contribute to their own care, but their loss would be stopped at a reasonable point along the way. For elders near poverty, such a plan would do little; Medicaid would need to be restructured to

pick up the premiums for those at 150% or 200% of the poverty level.

A public-private mix will not help those most in need. Older women need protection from long-term care costs more than any other group, but with incomes half the national average, they are least likely to be able to afford private insurance. In addition, even those elders who can afford it may still be faced with substantial out-of-pocket expenses because of policy limitations and occasionally marked changes in co-payment levels.

MARIANNE GONTARZ

Older women need protection from long-term care costs more than any other group, but with incomes half the national average, they are least likely to be able to afford private insurance.

ANDREA PERI ROSENFIELD

PROTECTING FAMILIES AND THE POOR

In reshaping America's long-term care policy, two groups deserve special protection. One is the American family. Families provide 88% of care, and any policy must be designed to assist and encourage families, while not making their burden any greater. The second group is poor and near-poor elders. They need guarantees that they will be able to get long-term care when they need it, and that they will not be relegated to settings with second-class care.

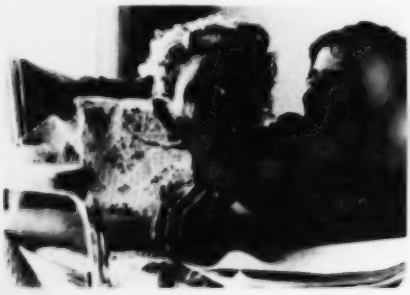
Families

Making the Family's Task Harder

America's long-term care system makes giving care difficult for families. First, very little public assistance is available for the non-intensive, inexpensive help that most disabled elders need. Public assistance is available only when an elder becomes impoverished and needs intensive and expensive nursing home care. Families must provide care for free, most of the time without outside help, until the task becomes too much. Perhaps a small amount of appropriate assistance earlier in the process would postpone the day caregiving becomes overwhelming. It would certainly make life easier for family caregivers.

A second feature creating hardship for families is the requirement that an elder must "spend down" assets to qualify for Medicaid. This requirement, in addition to assaulting an elder's dignity, also means that his or her spouse becomes impoverished. The elder who needs long-term care often dies, leaving the surviving spouse relatively poor, in spite of the saving and planning they may have done for their old age.

Some states, and now the federal government, through the Medicare Catastrophic Health Protection Act, provide some remediation of the damages of spousal impoverishment. In states that protect spouses from impoverishment, there are legal provisions for dividing the couple's assets, protecting some amount, usually half, for the spouse who does not need care. In the federal bill, spouses can protect a set monthly amount for living expenses, plus at least $12,000 of their joint assets, in addition to their home. This is, at least, minimal protection for the non-institutionalized spouse.



MARIANNE GONTARZ

Perhaps small amounts of appropriate assistance will keep family caregiving from becoming an overwhelming task.

Encouraging Families

Since families provide most long-term care informally and voluntarily, some policy makers fear that families will stop if more formal systems are in place. Evidence from demonstration projects and experiences in other industrialized nations with generous in-home benefits suggest otherwise. American families want to continue to care for older family members and are torn when they are no longer able—financially, physically or emotionally—to care for them at home. However, few government policies serve to encourage informal caregiving. In fact, one program, Supplemental Security Income (SSI), penalizes family caregiving. Benefits are reduced if the recipient lives with his or her family.

Recently, several state governments have enacted legislation that recognizes the important role families play in long-term care. The states of Maryland and Florida provide cash grants to families who agree to care for an elderly relative at home. New York has a home attendant program, where the elderly client is permitted to choose the attendant, including a relative. It is difficult to assess how expensive it would be to expand similar programs nationwide. Further, we do not know whether these families would be providing care regardless of the incentives. Recent studies suggest that economic incentives may not be the most effective means of encouraging potential caregivers. The primary burden is emotional, not economic. Expanding social support networks and respite care services might do more to encourage families to give long-term care. Policy makers must also anticipate that since women provide most of the caregiving, informal support may decline in the future. Given women's increased participation in the work force, declining fertility rates, and increased mobility, fewer women, especially adult daughters, will be available as caregivers.

Pressures on Older Women

As we face a society in which there will be a greater number of dependent older persons, the question arises: Who is responsible for caregiving? As the late Tish Sommers, co-founder of the Older Women's League phrased it, "Why is caregiving not seen as a common problem to be shared economically

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Many women face challenges as caregivers of the young and the old while working full-time jobs.

and practically by the whole society?" Women have traditionally accepted the role of caregiver, yet our economic system does not recognize that labor. Women who do not enter the labor force or leave it early to care for an elderly relative lose income, Social Security credits, and pension contributions. They will, in turn, become the next generation of older women living in poverty, especially if they are also members of a minority group. While child care still remains an unresolved issue on the American political agenda for younger working women, elder care is becoming just as pressing an issue for older working women, with middle-aged working women sandwiched between the two demands.

If a new system does not redistribute long-term care funding to create a continuum of services, supporting home and community care as well as institutional care, families will continue to struggle along, caring for their loved ones at home in spite of the system. That is where elders want to be and where families want them to be.

The Poor

The Medicaid Program

Medicaid gives low-income elders who are eligible substantial help paying medical bills. Medicaid pays Medicare premiums, deductibles, and coinsurance for nearly three million older Americans. Although state coverage varies, Medicaid generally pays for prescription drugs, dental care, eyeglasses, hearing aids and preventive care such as flu shots. The aged poor often desperately need these items, but cannot afford them without substantial assistance.

Above all, Medicaid covers long-term care that Medicare does not cover, both in the home and in nursing homes. Medicaid also covers many older people who are not poor to begin with, but who become impoverished by the cost of chronic care.

The Frayed Safety Net

Although Congress established Medicaid in 1965 as a safety net to protect the poor, during the past eight years, the system's substantial holes have become even wider. Eligibility requirements and benefits vary among states, resulting in unequal treatment of the aged. Personal care services under Medicaid remain underused because of state restrictions aimed at controlling costs. Elders who are eligible for Medicaid nursing home coverage are often treated as second class citizens. Many facilities refuse admittance to Medicaid patients, since reimbursements are lower than the fees private patients pay. Other nursing homes take on private pay patients, only to discharge them—questionable both ethically and legally—once their resources are exhausted and Medicaid must finance their care.

Designed as a health care program for the poor of all ages, Medicaid has evolved into the principal federal program providing long-term care. Now 43% of its total budget supports nursing home care for elders, 70% of who are older, white women. This expenditure significantly affects Medicaid's ability to meet the needs of other low income people. It also distorts, on a larger scale, the philosophy that lies behind means-tested programs. Large numbers of formerly middle-class elders become dependent on Medicaid for a long period of time without hope of moving out of the system.

However, near-poor elders face the most severe barriers to obtaining medical care. While approximately 12.5 million American elders live in poverty, in 1985 another 5.7 million older people were living at or below 125% of the poverty level. Forty-five percent of older blacks and 35% of older Hispanics lived at this level or below. Ap-

proximately 42% of all elders live within 200% of the poverty line. For a single person, this means an income of approximately $10,000 a year. These elders do not qualify for Medicaid assistance, yet they also lack adequate income to provide for their own health care or long-term care. These are the elders most likely to fall through the safety net of our social policies. Recent studies report that the poor and near-poor with Medicare alone average 4.2 physician visits annually, compared to 7 visits for the same income group that has both Medicare and private health insurance.

Public vs. Private Financing

The effects of proposed new long-term care systems on the poor must be weighed. Those who favor a public universal program, with eligibility based on functional disability (and not income), argue that only this approach will truly eliminate the current second-class treatment of Medicaid recipients and equally protect the poor. A means-tested long-term care program serving only the poor would have a built-in weakness. Historically, such programs have fared poorly in Congress. For example, during the 1980s, there has been much more political support for the universal Social Security program than the means-tested Aid to Families with Dependent Children ("welfare").

Those who favor a private insurance model counter that if middle class people who have exhausted their funds were not the prime beneficiaries of Medicaid, Medicaid could spend more on protecting the poor and near-poor.

Whichever choice we make, any proposals with sizable premiums, deductibles or co-payments will keep the poor and near-poor from getting care that they need.

PAYMENT STRATEGIES TO ASSURE ELDERS MORE OPTIONS

How can America best provide a variety of long-term care services efficiently and cost-effectively? During the last decade, state innovations and experiments have offered many valuable lessons about coordinating payment for services and controlling Medicaid expenditures. These should be applied to designing future long-term care systems at the state and federal level. Three strategies now being widely applied are prospective payment, client-centered reimbursement and case management. In addition, there are a few promising experiments in combining the management and financing of care.

Prospective Payment

Controlling costs has become the dominant theme in health care policy debates. One cost containment strategy is prospective payment, where providers know in advance their reimbursement for each service. Prospective payment is currently used for Medicare. Medicare pays a fixed amount for each of 467 diagnosis-related groups as reimbursement for all services required to treat the patient. Prospective payment was adopted for Medicare to foster competitiveness among providers in the private market, while maintaining cost discipline. State governments have shown interest in this system for long-term care; the most common long-term care reimbursement change among states during the last decade has been a shift to a prospective payment system.

In theory, a prospective payment system encourages providers to economize, since they know their levels of reimbursement in advance. The difference between providers' cost and reimbursement is their profit (or their loss). Research on the effect of prospective reimbursement has found that it does significantly lower the per diem rate for nursing home care. One study suggests that it slows the increase in nursing home costs without decreasing access to care. Possibly this is because prospective payment provides an incentive for administrators to control wages, a major cost determinant, but also the source of potential problems—depending upon whose wages are controlled.

Client-Centered Reimbursement

For a long time, states reimbursed nursing homes on the basis of the level of care provided. Generally, there were two categories, intermediate and skilled. There were also slight variations for regional cost differences. Some states also adopted a ceiling above which charges would not be reimbursed. During the last decade, however, reimbursement has shifted from this level of care approach to a "client centered" or "case mix" approach. The previous reimbursement system offered little incentive for service providers to accept patients needing more intensive levels of care.

Several different strategies for client centered reimbursement have been developed, among them the Illinois Point-Counter Approach; the San Diego Incentive-Reimbursement Experiment conducted by the National Center for Health Services Research; the Outcome-Based Reimbursement study conducted by Robert Kane and researchers at Rand Corporation, and the RUGS (Resource Utilization Groups) approach developed by Schneider and colleagues at Rensselaer Polytechnic Institute in Troy, New York and now in place in New York State. With all

strategies, reimbursement is tied to a rating based on the patient's need for care.

This approach has inherent difficulties. First, assessment ratings are not always reliable. Second, since the condition of patients is constantly changing, they must be reevaluated frequently, which is expensive. Perhaps the most serious flaw is the perverse incentive for service providers to encourage more dependent conditions so that patients will qualify for higher reimbursement. Under this model, as the patient improves, reimbursement decreases.

Case Management

Case management is emerging as a framework for solving some of the problems in our fragmented, limited and costly long-term care system. The goal of case management is to overcome the difficulties that the present organization and delivery of long-term care presents by individualizing and integrating social and health needs; providing clients with access to a continuum of care; and assuring appropriate levels of care. A case manager coordinates entry into the long-term care system and access to care; he or she screens clients, assesses them, determines what services they are eligible for, plans their care, and arranges services. The case manager also follows up and alters the services as necessary.

Two models of case management have developed: a "brokerage" and a "consolidated" model. A case management broker coordinates existing long-term care resources and is completely separate from the direct provision of services, except for limited filling of gaps. Under the consolidated model, on the other hand, a single provider organization is responsible for service management and delivery.

Brokerage Model

In a brokered system, case managers have primary responsibility for comprehensive assessment, followed by referrals to a wide range of institutional and non-institutional care providers. This system relies on existing providers for direct care and adds another organizational layer to the already existing system. A brokered model has the advantage of maximizing existing community resources and eliminating duplication of services. A case management program separated from the service provider also reduces potential for conflict of interest. (A provider-based case manager has an incentive to prescribe care to match the provider's available services.) A brokered model is also the easiest to implement in the short run.

To date there is little conclusive evidence as to whether this type of case management is cost effective or whether it successfully reduces fragmentation. Two primary difficulties are associated with the brokerage model. First, while its case managers can refer clients to services, they cannot guarantee access to services. Second, as a referral source, case managers have little or no control over provider policies, costs or quality.

Consolidated Model

Under a consolidated model of case management, one organization provides assessment, manages care, and provides services. For the client, this model offers guaranteed access to needed services. Multiple services can be coordinated to meet the client's complex needs. A higher degree of visibility makes it easier for people to enter the system. On a broader level, greater authority and responsibility lodged in a consolidated system might lead to a reshaping of social and health care services for elders, providing more options outside of nursing homes. Further, this model eliminates the need to separate case management from the

delivery of services, which could potentially reduce costs.

Yet there are also a number of potential drawbacks to this model. It may create a service monopoly that is protected from quality and cost competition. Other service providers would no doubt oppose a consolidated organization, seeing it as competing with the services they offer. Further, the potential for ethical conflict is always present: Who is the case manager's client—the overall agency or the elder? Cost containment efforts may work in opposition to client need. Certainly, there are ways to address this issue, but sensitive awareness of it is critical.

Combining the Financing and Management of Care: S/HMO and On Lok

Known as managed care plans, such plans are financially at risk and so have built-in incentives to control costs. They are also useful tools for arranging the most appropriate level and type of care.

S/HMO

Social/Health Maintenance Organizations are a new idea based on Health Maintenance Organizations (HMOs). For acute medical care, HMOs have become alternatives to private health insurance and fee for service. The HMO charges the client a fixed fee, and clients receive a broad range of health care services, from office visits to hospitalization. Some services are excluded, and clients sometimes pay small additional charges for services. HMOs may be organized around a single institution, as with the Kaiser system in western states. An HMO may also link a network of private physicians, clinics, hospitals and other providers through their prepaid plan. HMOs, with their incentives to provide preventive care and disincentive to provide unnecessary care, often cut the cost of medical care.

Social/Health Maintenance demonstrations are experiments with consolidated models of long-term care. Four S/HMO models are currently being tested in a federally-assisted nationwide demonstration conducted by the University Health Policy Consortium at Brandeis University. The S/HMOs combine a full range of acute and chronic health care services in one system. Each demonstration project was required to enroll a membership that reflected their community, with both healthy and impaired individuals. Members pay premiums in advance, and the sponsoring agency must provide all needed services from the pool of funds generated by these premiums. The S/HMOs, using case

Table 5.
Private Premiums and Chronic Care Benefits of S/HMO Demonstration Sites

Site	Monthly Premium	Annual Chronic Care Benefit	Renewability of Institutional Benefits
Kaiser	$49	100 days nursing home; $1,000 per month home/community	Only for new "spell of illness"
Metropolitan Jewish Geriatric Center	$29	$6,500 in any setting	Fully renewable
Ebenezer	$29	$6,250 in any setting	$8,000 lifetime
Senior Care Action Network	$40	$7,500 in any setting	Fully renewable

Source: Jay Greenberg *et. al.*, "The Social/Health Maintenance Organization and Long-Term Care," *Generations*, Summer, 1985.

management, emphasize preventive and non-medical care, and home and community-based care over nursing home care. Table 5 (see page 34) shows the monthly premiums and coverage at each of the four sites. The three-year experiment has been underway since 1985. When the data analysis is complete, it should offer valuable information about service utilization and costs under an insured, prepaid system of long-term care serving a group representative of the national Medicare population, a population not at particularly high risk for needing long-term care.

On Lok

Unlike most prepaid systems, which try to screen out high risk users, On Lok in San Francisco provides an example of a prepaid model providing community-based long-term care to a high risk population of elders. The package of services provided by On Lok is comprehensive, covering nursing home, hospital, medical and home health services, with a heavy emphasis on day care. The average cost per person of maintaining an elder in On Lok's program was $2,200 per month in 1989. Private funds paid for about 4%, Medicare 29%, and Medicaid 67%. As a prepaid approach successfully serving an extremely frail population, the On Lok model is being replicated through demonstrations in eight other states.

Unlike most prepaid long-term care organizations, On Lok in San Francisco's Chinatown targets an extremely frail population of elders.

CONCLUSION: THE CHALLENGE WE FACE

If America is to develop a new system of long-term care, we must answer some difficult questions. How much risk are we, as a society, prepared to assume? How do we distribute the burden of financing long-term care among family, individuals and the public sector? Should middle-class older people continue to risk poverty if they become disabled and need care?

A crisis is simmering in our present long-term care system, not just for older people, but for the whole American family and for disabled people of all ages. To avert it, we need better funding and organization. We need a system that makes long-term care affordable for the majority of Americans. We need to guarantee that services are accessible, with no long waiting lists. The system must be fair. Access to care must be equally distributed, regardless of income or ethnic background. Any national long-term care system must create a continuum of care, so elders with functional disabilities (and all who need services) can receive the appropriate level of care, without losing their personal autonomy or independence because the only alternative is a nursing home.

A new system must assure quality care, both in the community and in institutions. Regulators and providers have long been concerned with the quality of care in nursing homes. But insuring quality of care in a home setting is even more challenging; it is more difficult to monitor and regulate care in an individual home. Profit-making agencies are the fastest growing segment of the home care industry today. While profit is not automatically incompatible with providing quality care, we need services and reimbursement policies that encourage quality care for people who may not be able to speak for themselves.

Clearly, America is still building its long-term care system. Whether that building occurs incrementally through step-by-step changes, or through major new legislation, depends in great part on how the President and Congress read the will of the American people. While we have the expertise to design a new long-term care system, what we need today is the leadership to make it happen.

MARIANNE GONTARZ

APPENDIX A:
WHERE ARE WE HEADING? CURRENT ACTION BY STATE GOVERNMENTS

A Pressing Issue

Long-term care is one of the most pressing issues facing state governments today. Because federal administrations in recent years have opposed new programs on budget and philosophical grounds, most action on long-term care has taken place at the state level. However, many social and economic factors beyond state control make it difficult for states to develop affordable and practical policies to meet growing needs.

States are particularly at risk for long-term care costs. Medicaid, the only public program that funds nursing home care, is administered by states and jointly funded by federal and state governments. In 1985, the Medicaid program spent $14.7 billion for nursing home care, approximately 43% of its total budget. Health care, including long-term care, is the most rapidly rising segment of state budgets.

The critical year for Medicaid was 1981, when the Reagan administration proposed a tight 5% limit on the increase in the 1982 Medicaid budget. At that time, inflation in health care was exceeding 15% and hospital expenditures were rising by nearly 20% annually.

Threatened with impending cuts, a powerful coalition of Medicaid supporters emerged. Governors recognized that Medicaid was their largest source of federal dollars. The business community recognized that Medicaid pays for services that otherwise would be shifted to employment-based private insurance premiums. Elders sought protection for the Medicaid program, since it provides almost half of the revenue for nursing home care. Advocates for the disabled, mentally retarded, and child and maternal health programs also joined the fray. These forces, and their Congressional sympathizers, united to defeat the Reagan administration's annual efforts to squeeze Medicaid.

The resulting federal budget compromise, enacted in the Omnibus Budget Reconciliation Act of 1981 (OBRA), created a "rebate" incentive system for states to control Medicaid expenditures. Furthermore, OBRA allowed states achieving overall cost containment to restructure key features of the Medicaid program at the state level. This restructuring allowed waivers (the 2176 program), to divert funds from nursing home care to alternative services based at home or in the community.

While federal budget cutting pressured Medicaid, federal funds for long-term care outside of nursing homes were also being slashed. Throughout the 1970s, Title XX (Social Services) of the Social Security Act had supported an increasingly large share of community-based long-term care services. In 1981, Congress converted Title XX to a block grant (SSBG), significantly reducing and capping what had been an expanding flow of federal dollars. At the same time, they eliminated federal revenue sharing dollars, which had also been used to develop alternatives to nursing home care. The final source of federal funding for non-institutional care, the Older Americans Act, has been stable, but relatively insignificant in terms of available dollars.

Faced with these immense budgetary constraints and the growing older population in need of long-term care, states have moved aggressively to redesign local delivery sys-

tems and funding structures. Although these efforts differ from state to state, generally states have:

- ▼ Reorganized state departments overseeing long-term care;
- ▼ Reorganized local delivery systems to include assessment and case management, in order to provide more appropriate levels of care and avoid unnecessary, and costly, nursing home stays;
- ▼ Constrained the growth in nursing homes and diverted savings to community care;
- ▼ Developed new financing mechanisms through 2176 waivers, and the infusion of state revenues;
- ▼ Investigated, and in some instances, designed, private long-term care options, including private long-term care insurance policies, continuing care retirement communities, and home equity conversion loans;
- ▼ Developed new services to fill in numerous gaps;
- ▼ Defined and targeted those in the community deemed most vulnerable;
- ▼ Developed more equitable cost-sharing methods for those receiving long-term care services;
- ▼ Begun regulating, through state insurance commissions, the emerging private long-term care insurance industry.

This state level action has resulted in a vastly improved array of services, increased use of community-based services, a more appropriate management of resources, and policies that support informal caregivers. However, current structuring and financing is still inadequate to meet current, much less future, needs. For example, as a result of the bias in Medicaid, the long-term care system is still heavily weighted toward reimbursement for nursing home care, with tight restrictions on in-home and community-based care. Further, the discomfort most middle-class elderly experience in becoming reliant on needs-based programs like Medicaid remains unchanged.

While many states have demonstrated their commitment to improving the long-term care delivery system, it is clear that a similar commitment is necessary at the federal level in order to meet projected needs, and offer more access to care outside of nursing homes.

State Innovations

Federal budget cutting during the 1980s has meant that the majority of spending for home and community-based long-term care has come from state and local sources. States have developed a broad range of organizational and funding innovations; two of special interest are those in Minnesota and Oregon.

Minnesota: Diverting Elders from the Nursing Home

Minnesota had one of the highest percentages of elders in nursing homes in the country, approximately 9%, compared to 5% nationwide. It ranked second nationally in the amount of Medicaid dollars spent on nursing home care. After an extensive review of long-term care costs, the state implemented a pilot pre-admission screening (PAS) program in 1980. The following year, pre-admission screening was expanded statewide. The Alternative Community Grants (ACG) program funds screening and services as an alternative to nursing home placement. To be eligible, a client must be at risk of nursing home placement. Services include case management, personal care, home health aides, homemakers, adult day care, respite care and adult foster care.

Through this comprehensive gatekeeper program, Minnesota has diverted a significant number of clients from nursing home care. There are still unresolved problems in

the alternative care delivery system. In most counties, the ACG program is not well coordinated with the Community Social Service system (Title XX and state/local funds for social services) or with services funded by Title III (Older Americans Act). PAS/ACG is but one entry point into the long-term care system, and misses the full potential of a system with a single entry point. A single entry point eases the burden on elders and their families as they seek appropriate long-term care services. It also can substantially reduce paperwork and thereby administrative costs.

Oregon: A Comprehensive Community-Based System

Oregon, on the other hand, has been successful in creating a single entry point into the long-term care system. In 1981, Oregon reorganized its long-term care components under the Senior Services Division of the State Department of Human Services. At the local level, area agencies on aging (AAAs) manage the system under state supervision. This comprehensive local management includes all community-based services, and, in addition, Oregon is the only state where AAAs have administrative responsibility for nursing home placement and utilization. Within the next year, by using pre-admission screening and developing alternative care settings, Oregon was able to relocate 4,103 nursing home patients back into the community.

In 1984, the Senior Services Division assumed responsibility for determining financial eligibility and food stamps for elders, thus enabling clients to be in contact with a single case manager for eligibility determination, planning and service coordination. Later in 1984, nine of the eighteen AAAs in Oregon elected to assume responsibility for long-term care management. The role of the state bureaucracy was redefined from direct control and management to monitoring, evaluating and providing technical assistance.

In 1985, Oregon's Senior Services Division assumed inspections of care and utilization review for nursing home and alternative care service providers. With the rapid expansion of foster care as a community-based long-term care alternative, Oregon began foster home licensing in 1986 in order to monitor quality and life safety standards. Nursing home reimbursement was also restructured in 1986 from a retrospective to a prospective system.

While Oregon has been successful in developing a comprehensive community-based system, Oregon officials recognize its limitations. There is a shortage of qualified nursing and nursing assistants. Case managers have high caseloads. There are pressures to increase reimbursement levels. Physicians and hospitals are reluctant to refer patients to community-based alternatives. The public is not aware of nursing home alternatives, and resources are not sufficient to meet the need.

State Efforts Offer Hope

Other states have taken action similar to that in Minnesota and Oregon: reorganizing their bureaucracies, consolidating funding sources, streamlining eligibility requirements and reducing system fragmentation and duplication of services.

These experiences offer valuable lessons about the need to coordinate Medicaid benefits with other federal and state long-term care programs and the difficulties encountered when reshaping an existing system. Nonetheless, as with the Canadian experience in developing a comprehensive system, these innovations offer hope that states can assure equal access to care while encouraging the development of locally-determined and appropriate services.

APPENDIX B: CONFERENCE SPEAKERS*

Robert Ball, Visiting Scholar, Center for the Study of Social Policy

Carson Beadle, Managing Director, William M. Mercer-Meidinger-Hansen, Inc.

Bart Collopy, Ph.D., Associate for Ethical Studies, The Hastings Center

Dennis DeWitt, Executive Director, Task Force on Long Term Health Care Policies, Department of Health and Human Services

Pamela Doty, Ph.D., Senior Policy Analyst, Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services

Margaret Lynn Duggar, Program Staff Director, Florida Aging and Adult Services Division

Lynn Etheredge, Ph.D., Consultant, Consolidated Consulting Group

Msgr. Charles Fahey, Director, Third Age Center, Fordham University

Lou Glasse, President, Older Women's League

Willis Goldbeck, President, Washington Business Group on Health

Judy Heumann, Co-Director, World Institute on Disability

Edward Howard, J.D., Public Policy Coordinator, Villers Foundation

Aaron J. Johnson, Commissioner, Georgia Department of Medical Assistance

Robert Kane, M.D., Dean, School of Public Health, University of Minnesota

Rosalie Kane, DSW, Professor, School of Public Health, Division of Health Services Research and Policy, University of Minnesota

Paul Kerschner, Ph.D., Executive Director, National Foundation for Long Term Health Care

Richard Ladd, Administrator, Oregon State Senior Services Division

Peter Libassi, J.D., Senior Vice President, The Travelers

Barbara Manard, Ph.D., Principal, Lewin and Associates

Barbara Matula, Director, North Carolina Division of Medical Assistance

Stephen McConnell, Ph.D., Coordinator, Long Term Care '88, American Association of Retired Persons/Villers Advocacy Associates

Tom Moore Jr., Senior Researcher, Institute for Health and Aging, University of California, San Francisco and The Presidio Group

C. Kermit Phelps, Ph.D., Chairman of the Board, American Association of Retired Persons

John Rother, J.D., Director, Legislation, Research and Public Policy Division, American Association of Retired Persons

Anne R. Somers, D.Sc., Adjunct Professor, Department of Environmental and Community Medicine, New Jersey-Rutgers Medical School

Fernando Torres-Gil, Ph.D., Associate Professor of Gerontology and Public Administration, Andrus Gerontology Center, University of Southern California

Joshua Wiener, Ph.D. Senior Fellow, The Brookings Institution

Christine Williams, Legislative Aide to Senator George Mitchell (Maine), United States Senate

Paul Willging, Ph.D., Executive Vice President, American Health Care Association

*Positions at time of conference, January, 1988.

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